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Discussions of advance directives in the outpatient setting : why do they happen so rarely?

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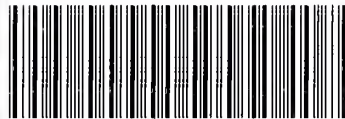
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DISCUSSIONS OF ADVANCE DIRECTIVES
IN THE OUTPATIENT SETTING:
WHY DO THEY HAPPEN SO RARELY?

Daniel T. Coghlin

1998

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Discussions of Advance Directives in the Outpatient Setting:
Why Do They Happen So Rarely?

A Thesis Submitted to the
Yale University School of Medicine
in Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

by

Daniel T. Coghlin

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ABSTRACT

Discussions of Advance Directives in the Outpatient Setting: Why Do They Happen So Rarely? Daniel T. Coghlin, Michele Despreaux, Angelie Maun, and Margaret Drickamer. Section of Geriatrics, Department of Internal Medicine, West Haven Veterans Affairs Hospital and Yale University School of Medicine, New Haven, CT.

This investigation examines the discussion of advance directives (AD's) in the outpatient setting to help to elucidate what is preventing patients from meaningfully participating in their own end-of-life treatment decisions. A thirteen-item questionnaire inquired about basic demographic and health-related information, patients' knowledge of and interest in advance directives, previous completion or discussion of advance directives with health care providers and others, the barriers to discussion of AD's with their physicians, and preferences regarding future discussions of advance directives. We administered questionnaires to outpatients at two primary care clinics, one at a VA and the other at a community HMO. This is a descriptive cross-sectional study.

Most were interested in learning more about AD's (68.5% at the VA and 85.3% at the HMO), but few respondents had ever discussed advance directives with their physicians (42 [13.8%] at the VA and 18 [11.7%] at the HMO). Of those that had, only 14.6% respondents at the VA and 6.2% at the HMO reported that the discussion made them feel at all uncomfortable. Although most respondents had never discussed AD's with their HCP, many of those who had not were interested in such a discussion (119 [47.2%] at the VA and 84 [65.6%] at the HMO). Neither age ($p=0.16$) nor self-reported health status ($p=0.87$) were correlated with interest in discussion. The most frequently chosen explanations for not previously discussing AD's with their physicians were that it did not occur to them to bring it up (56.7% at the VA and 60.6% at the HMO), and that the physician did not bring it up (22.0% at the VA and 20.6% at the HMO). Most respondents thought that an office visit was the most appropriate setting for discussion of AD's (166 [55.9%] at the VA and 100 [68.0%] at the HMO) and wanted to include a family member in the discussion.

Discussions of AD's with one's physician rarely happen. Although it is not easy to predict who wants to discuss AD's and who does not, physicians should offer to discuss them routinely with their patients in the outpatient setting. The vast majority of patients react favorably to the discussion, many are interested in discussing them, and the main barriers to discussing them from a patients' perspective could be overcome by physician initiation. Physicians should also encourage the patient to bring a significant other to the discussion.

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INTRODUCTION

Decisions concerning medical care near the end of life can be both mentally and physically anguishing for everyone involved. Historically, such decisions were left up to the physician, sometimes in consultation with the family. In recent years, however, individuals have been recognized as legitimate contributors to decisions regarding their own care near the end of life. This inclusion of individuals in their own treatment decisions reflects a general trend in modern thought, the emphasis on individual autonomy. As much as possible, people have a right to decide for themselves the course of their own lives.

With regard to end-of-life decisions, two ethical principles encourage individual autonomy when patients are no longer able to make decisions themselves, substituted judgment and beneficence. Substituted judgment is “the application of the patient’s preferences and values...trying to choose as the patient would have wanted.”¹. This concept helps the proxy decision makers to understand that their decision is based upon the patient’s preferences, not their own. It also applies to physicians who have previously spoken with patients about their end-of-life preferences, but whose current circumstances were not specifically addressed. By employing substituted judgment, the decision makers preserve as much of the patient’s autonomy as possible. If there is no information upon which to speculate what that individual would have wanted, the concept of beneficence still applies. Beneficence is the weighing of benefits, risks, and burdens of an intervention in the context of the individual. Deciding about interventions is then based upon a risk-benefit ratio individualized as much as possible to the patient’s circumstance.

To apply substituted judgment more thoroughly towards end-of-life decisions, advance directives were introduced. Advance directives are documents which state one’s preferences regarding life-sustaining treatment or establish a proxy to decide about such treatment in the event that the individual is unable to communicate his or her preferences directly. These documents were slow to gain widespread acceptance, but a court case and

a piece of Federal legislation thrust advance directives into the national spotlight in the early 1990's.

In 1991 a landmark United States Supreme Court decision, *Cruzan vs. the state of Missouri*², the right for individuals to participate in their own treatment decisions was unequivocally established. This court case confirmed that competent patients have a “constitutionally protected liberty interest in refusing unwanted treatment.” Competent individuals not only could participate in their own care, but had the clear right to refuse treatment, even for future care decisions. According to the *Cruzan* decision, individuals could establish their wishes regarding refusal of medical treatment in advance of the need to accept or refuse such treatment. Should such an individual become incapacitated, their previously expressed wishes regarding refusal of medical treatment must be followed.

Meanwhile, the United States Congress became involved. In concurrence with the *Cruzan* decision, Congress sought a way to help ensure that individuals understood that they had the right to refuse treatment and that health care providers would adhere to the individual's treatment preferences. To accomplish this joint task, Congress saw the discussion of advance directives as their answer. The Patient Self Determination Act mandated that any health care institution accepting Medicare funding must offer to discuss advance directives with patients upon their admission³.

Despite these efforts to preserve patient's wishes regarding end-of-life care, these wishes continue to go unheeded. A multicenter randomized controlled trial called the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) found that the presence of an advance directive did not significantly impact end-of-life treatment decisions.⁴ The SUPPORT study will be discussed in further depth later in the introduction. Another study found that advance directives did not enhance communication between physicians and patients regarding end-of-life decisions.⁵

These results suggest that AD's are not enough to improve the communication between HCP's and patients regarding end-of-life issues. Another important part of such

communication is patient education regarding the realities of end-of-life decisions. Many studies have shown that most people have a poor understanding of treatment decisions regarding the end of life, drastically overestimating the success of cardiopulmonary resuscitation⁶⁻¹¹. Most studies designed to help improve patients' understanding of end-of-life issues focus on AD's as the solution. This focus may not be the best approach, however, as learning about one's rights to direct end-of-life care is not necessarily similar to learning how to make a more informed decision about end-of-life care. While improving the completion rate and adherence to AD's may be laudable goals, HCP's should also keep in mind that educating patients about the realities of end-of-life decisions is important too.

Several studies have examined interventions designed to aid communication between the patient and the physician, with varying results. Some have focused on inpatient populations, others have focused on outpatient populations, while others have focused on physicians. While these interventions will be described in some detail in this introduction, please refer to Table One in Appendix A for a summary of these interventions.

1. Patient Interventions

A. Inpatient Interventions

Meier et al.¹² reported a randomized controlled trial of hospitalized patients that found that those patients who received counseling about AD's upon admission reported previous AD's more often and completed new AD's more often than those who were not counseled. This study did not examine the impact of this counseling on actual discussion of AD's with the physicians or examine the impact of the counseling on the patients' actual end-of-life management. Reilly et al.¹³ also found that a hospital-based intervention increased the frequency of AD completion.

B. Outpatient Interventions

Other studies have examined the impact of interventions in the outpatient setting.

Siegert et al.¹⁴ found that the use of an educational videotape about AD's did not significantly improve comprehension of selected AD-related concepts or significantly affect treatment preferences. A randomized controlled study of a military general medicine clinic found a significant increase of completion of advance directives (38% vs. 24% $p=0.04$) for those who had attended a one-hour educational seminar about AD's¹⁵. This study also noted an increase in discussions regarding end-of-life issues with one's physician (73% vs. 57% $p<0.05$). The frequency of discussion with one's AD was much higher for both the control group and the intervention group than in previously reported studies and in this one.

In a randomized controlled trial, Rubin et al.¹⁶ found that 18.5% of those who received a mailed educational pamphlet and forms completed an AD compared to 0.4% of the control group. However, Sachs et al.¹⁷ did not find a significant increase in completion of AD's when an educational form and reminder card were distributed. None of these studies examined the interventions' effects on actual end-of-life decisions.

2. Physician Interventions

Interventions regarding physician education have also been examined. Dunn et al.¹⁸ reported that the use of a coversheet physician orderset summarizing the patient's preferences for end-of-life treatment improved the agreement between the patient's preference and the decisions made by physicians participating in a focus group who were asked to decide what they would do when presented with several case scenarios. This study did not examine this coversheet's impact on actual end-of-life decisions, only theoretical scenarios. In an observational study of a convenience sample at a geriatric clinic in a tertiary care hospital, Meier et al.¹⁹ reported that a one-hour educational seminar for physicians and subsequent initiation of discussion by the physician increased the number of AD's documented in charts from 2.3% before the intervention to 31.5% after the intervention. Sulmasy et al.²⁰ reports about the impact of educational pamphlets for

patients (patient-education) and of lectures and sample videotaped discussions for residents (resident-education). Documented AD discussions with patients in the resident-education group increased from 3 to 17% ($p<0.05$), and did not significantly increase in the patient-education group. Neither intervention increased the number of charts with an AD. Markson²¹ reports that physician training involving observed sample discussions lead to an increase in patients completing AD's when compared to the same physicians' patients before the intervention. These studies suggest that educating physicians increased the number of discussions about AD's.

3. The SUPPORT Intervention

The most comprehensive intervention designed to improve communication of patients' preferences for end-of-life decision making was the SUPPORT study²². SUPPORT looked at patients admitted to five tertiary care teaching hospitals. Patients were selected who had at least one of nine different life-threatening diagnoses, carrying an overall 6-month mortality of 47%. The intervention included having a nurse visit the subjects and offer to discuss with them any aspects of AD's they would like to discuss. The nurses then passed along a report of the patient's preferences to his or her physician. The intervention also included prognostic information given to the physician regarding the patients' survival times, outcome of CPR, and likelihood of a severe disability. SUPPORT examined five outcome measures to assess the impact of AD's and of this intervention. The outcomes were the following: 1) the timing of DNR's, 2) patient and physician agreement on preferences to withhold resuscitation, 3) days spent in an ICU, receiving mechanical ventilation, or comatose before death, 4) the frequency and severity of pain, and 5) hospital resource use.

Unfortunately, this intervention did not improve any of the five aforementioned outcome measures, once the results were adjusted for diagnosis, age, and disease severity. Please refer to Table Two in Appendix A for a summary of these outcome results. Those with AD's were more likely to have a DNR order prior to being discharged from the

hospital (36.7% of those with an AD compared with 25.5% of those without an AD, $p < 0.05$). However, even this slight increase in patient and physician agreement on the preferences to withhold resuscitation is not statistically significant (95% confidence interval 0.96-1.46). Amazingly, having an AD also had no significant effect on the likelihood of undergoing CPR within one day of death. Of those who died during the initial hospital stay, 13.0% of those with an AD underwent CPR within one day of death, compared to 12.2% for those who had no AD²³.

These outcome measures did not improve despite the fact that the intervention group was 1.6 times more likely to have expressed their wishes regarding CPR to their physician²³, a poor reflection of physicians' adherence to their patients' wishes. Equally disconcerting, the physicians received at least one prognostic report for 94% of the patients and received a report of the patients' preferences in 78% of the cases. However, only 59% of the physicians acknowledged receiving such a report and 34% acknowledged receiving the patients' preference reports.

What is striking about all of these interventions is that very few showed any difference in communication between physicians and patients and none showed an effect on actual end-of-life decisions. Some demonstrated an increase in advance directive documentation, but the SUPPORT study found no demonstrable impact of AD's on end-of-life decisions. Patients still rarely discuss end-of-life issues with their doctors, do not know much about advance directives, and doctors have not engaged the patients in the discussions or honored their wishes in the decisions. Even so, this does not mean that improving end-of-life decisionmaking is a hopeless cause. As Linda Emanuel puts it,

[SUPPORT's] failure is also attributable to the intervention. Barriers to change in communication, social structure, and decisionmaking are indeed, as the investigators say, "substantial." But this should not matter. A successful intervention should target areas that are amenable to change, circumventing or working with deeply rooted aspects of human nature and culture. The issue is now to set a better goal, identify the barriers, and then construct a well-examined intervention²⁴.

This study's "better goal" is to improve the ongoing dialog between patients and physicians regarding end-of-life decisions. As dialog involves a continuing discussion over an extended period of time, we think that this discussion should begin before the patient is very ill, as they were in the SUPPORT study (with patients' overall 6-month mortality of 47%). If patients can begin to think about their treatment preferences before they become acutely ill and discuss these options with their physicians as an outpatient, they will likely be making a more informed, unrushed decision. Mainly for this reason, we chose to study the discussion of AD's in the outpatient setting. Another reason for studying the outpatient setting is that the Patient Self-Determination Act already compels most health care institutions to offer to offer to discuss AD's with inpatients. To examine the outpatient discussion of AD's, we look at outpatients' understanding of AD's, their previous experience with advance directives, completion or discussion of advance directives with health care providers and others, and wishes regarding discussing advance directives

No study, including SUPPORT, has been able to answer whether increased communication with one's physician about AD's improves the likelihood that the individual's preference will be followed. We know all too well, however, that AD's alone do not improve communication or adherence to patients' preferences. One crucial question remains: will an improved dialog between the physician and the patient about end-of-life decisions improve agreement about the actual decisions at the end of life? Our investigation assumes that the answer to this question is yes. To repeat, improving this dialog is the "goal."

To help understand how such dialog could be improved, we examine the "barriers" to discussion of advance directives in the outpatient setting. Specifically, we focus on patients' interest in discussing AD's, the barriers they describe to communication of end-of-life decisions, and their preferences for such discussions. Our working hypothesis is the following: By interviewing outpatients about their knowledge of AD's and their

preferences for discussion, we will be able to define barriers to communication where interventions could help increase the communication between physicians and outpatients regarding end-of-life decisions.

Such findings may provide information for a future study to design an intervention that increases the dialog between HCP and patient regarding end-of-life decisions more effectively than SUPPORT's interventions did. Such an intervention would be the final aspect of Linda Emanuel's three-step solution of finding a better goal than SUPPORT's, identifying the barriers, and designing a well-examined intervention. This future study may then be able use this intervention in a randomized controlled trial to answer that crucial question: Will an improved dialog between the physician and the patient about end-of-life decisions improve agreement about the actual decisions at the end of life and allow patients to meaningfully participate in their own end-of-life decisions?

STATEMENT OF PURPOSE

By interviewing outpatients about their knowledge of AD's and their preferences for discussion, we will be able to define barriers to communication where interventions could help increase the communication between physicians and outpatients regarding end-of-life decisions.

METHODS

A questionnaire was designed by consensus of the investigators, reviewed by colleagues, and piloted on a small sample of patients for ease of administration. The questionnaire included a brief introduction defining the terms "advance directives," "living will," and "durable power of attorney for health care." See the Appendix B for a copy of the questionnaire. The thirteen questions inquired about basic demographic information, patients' knowledge of AD's, previous experience with AD's, completion or discussion of AD's with health care providers and others, and wishes regarding discussing AD's. Because patients were seeing physicians or nurse practitioners, the inclusive term "health care practitioner (HCP)" will be used to refer to the physician or nurse practitioner.

A convenience cohort of patients was recruited at two sites: the primary care practice at a VA and an HMO. The primary care practice at the West Haven VA is an outpatient clinic serving more than 5,000 veterans and staffed by attending HCP's and nurse practitioners. On selected days, the investigator (DC) approached all patients after they had registered in the clinic and asked them if they would agree to participate. Patients were excluded from the study only for the inability to communicate (due to cognitive, functional, or language difficulties) or for lack of time to complete the questionnaire. The patients completed the questionnaire while waiting to see their health care provider. The questionnaire was self-administered, although the investigator was available to answer questions.

The second site, CHC Physicians, is a community-based HMO in the New Haven, Connecticut area with a general internal medicine clinic. At this site, an investigator (AM) left questionnaires in the waiting area at the HMO for patients to complete. As was done at the VA, the patients completed the questionnaire while waiting to see their health care provider, the questionnaire was self-administered, but the investigator was not always available to answer questions. No data was recorded about those patients who declined to participate.

Demographics included age, race, sex, marital status, religion, level of education, number of hospitalizations as an adult, and self-reported health status. Self-reported health status was determined by an analog scale. The questionnaire had a 10 centimeter line, representing the spectrum of health. The extreme left end of line represented perfect health, and the extreme right end of the line represented very serious, life-threatening illness. Patients were asked to place an "X" somewhere along the line to indicate where they considered themselves to be along this spectrum of health. The measurement in centimeters from the left edge of this line to the "X" was used for data analysis. To find out how long patients had been visiting their HCP, they were asked to choose one of the following choices: first visit, less than a year, between one and five years, and more than five years.

Questions concerning patients' knowledge of AD's included had they heard of AD's, living wills, or durable powers of attorney for health care, and had they thought about treatment decisions near the end of life.

Questions concerning previous completion or experience with AD's included if they had a living will or durable power of attorney and whether they had discussed AD's with their doctor. If they had discussed them, they were asked who initiated the discussion and how the discussion made them feel. Patients were asked to choose from a list of responses for how the discussion made them feel, including "comfortable," "slightly comfortable," "very uncomfortable," and "neutral." If they had not discussed them, they were given a selection of explanations why they might not have done so and asked to choose as many from that list as applied to them. Participants were given the opportunity to write in an explanation as well. They were also asked if they would like to discuss them with their HCP and if they had discussed AD's with anyone else besides their HCP.

Questions concerning wishes about discussing AD's included the following: who they thought should be the initiator of the discussion, themselves, their HCP, or both; in

what clinical setting they would like the discussion to take place; who else should be included in such a discussion; whether they would like educational material about AD's; and how important they thought it was to discuss AD's compared to other topics when talking with their HCP. To determine how important it was for them to discuss AD's another analog scale was used in the same way as previously discussed, with the left end representing "not at all important" and the right end representing "the most important." The questionnaire took approximately ten minutes to complete.

Because of discrepancies in data collection and issues of clinical utility, all data is presented separately for these two sites. There were three discrepancies between the two sites. First, each of the two interviewers interviewed exclusively at one site, with one interviewer available for questions, potentiating interviewer bias. Second, subjects were approached to participate at the VA, while patients elected to fill out the questionnaire at the HMO, potentiating patient selection bias. Third, data regarding those who refused was incomplete at the HMO site. Furthermore, we think that keeping the two clinic populations separate may prove useful for clinicians whose patients' demographics resemble one site more than the other.

Demographic data and responses to the questionnaire were compiled using EpiInfo and analyzed using descriptive statistics, including percentages, means, and standard deviations. Associations between demographic variables and attitudes toward AD's were examined using the chi-square test of association for dichotomous variables and the t-test for continuous variables, with $p < 0.05$ considered statistically significant. The study was approved by the Human Investigations Committee (HIC) at the VA and the HIC at CHC Physicians. All patients gave verbal informed consent to participate in the survey.

RESULTS

I. Study Population

VA

A total of 408 eligible patients were invited to participate in the study. 308 (75%) completed the questionnaire. For the 100 patients who did not participate, major reasons for refusal included (1) did not want to participate in any survey (49%); (2) the topic of the study (20%); and (3) not feeling well enough (14%). Comparing those who refused to participate with those who agreed, there was no significant difference in age, sex, marital status, and religion. No other demographic information was available for those who refused to participate. Table Three displays this demographic information in Appendix A. For the VA, the mean age of those who completed the questionnaire was 64.8 years (S.D. of 11.4). Those who were less than 55 years old made up 20.6% of the population, 66.7% were between 55 and 75 years old, and 12.7% were older than 75. The vast majority of the respondents were male (97%) and Caucasian (86.6%). The majority were Catholic, and 60% were married. The population was fairly well educated, with 84% completing high school or having some higher education.

Most respondents had seen their health care practitioner (HCP) for at least a year (63.1%), while 12.7% were making their first visit. Most of the respondents had been hospitalized at least once as an adult (91.5%), and almost half had been hospitalized four or more times (45.7%). By self-report on analog scale, the mean health rating was 5.69 out of 10.0 (S.D. of 2.85).

HMO

At the HMO, 156 patients attending the general medicine clinic volunteered to participate in the study. Table Three displays this demographic information in Appendix A. The mean age was 54, with a standard deviation of 17.6. Those who were less than 55 years old made up 54.5% of the population, 30.1% were between 55 and 75 years old, and 15.4% were older than 75. Most (66%) were female. Sixty percent were married,

70% were Caucasian, 19% were African-American, and 93% had completed high school or further education.

Seventy-one percent had seen their primary care provider for at least a year, while 5.1% were making their first visit. 84.4% had been hospitalized as an adult at least once, and 39.4% had been hospitalized four or more times. By self-report on analog scale, the mean health rating was 7.16 out of 10.0 (S.D. of 2.94).

II. Awareness and Prevalence of Advance Directives

VA

Most of the respondents had heard of the terms *living will* (88.2%) and *power of attorney* (73.7%), but less than half had heard of *advance directive* (41.2%). Only 60 respondents (19.9%) reported having a living will, and 56 (18.5%) had a power of attorney for health care. Neither age ($p=0.65$), number of hospitalizations ($p=0.13$), nor self-reported health status ($p=0.50$) was associated with completion of an AD. In contrast, most respondents indicated that they had thought about what sort of treatment they would want if they developed a life-threatening illness (203 [67%]).

HMO

Most of the respondents had heard of the terms *living will* (88.1%) and *power of attorney* (70.3%), but only 27.9% had heard of the term *advance directive*. Only 36 respondents (24.0%) reported having a living will, and 16 (10.3%) had a power of attorney for health care. Older age was a strong predictor of completion of an AD (mean age of 50.5 vs. 65.7 [$p=0.000025$]), as was increased number of hospitalizations (mean of 2.69 vs. 3.98 [$p=0.0023$]). Self-reported health status was not associated with completion of an AD ($p=0.13$). Here also, most respondents indicated that they had thought about what sort of treatment they would want if they developed a life-threatening illness (112 [71.3%]).

III. Respondents Who Had Previously Discussed AD's With HCP

VA

Few respondents had discussed advance directives with their HCP's (42 [13.8%]). These patients had a lower self-reported health status (mean 4.698 vs. 5.848, $p=0.015$) and more hospitalizations (mean of 4.071 vs. 3.338, $p=0.046$), but did not differ in age ($p=0.58$) from those who had never discussed AD's with their HCP. Only six (14.6%) respondents reported that the discussion made them feel at all uncomfortable. The respondent was most frequently the initiator of the discussion (20 [47.8%]). The HCP initiated the discussion in sixteen cases (38.7%). Other initiators included the family (2 [4.7%]) and an attorney (2 [4.7%]).

HMO

Few respondents had discussed advance directives with their HCP's (18 [11.7%]), but most of those who had done so considered the discussion to be a positive experience. Those patients who had discussed AD's with their HCP did not differ in self-reported health status ($p=0.23$), age ($p=0.59$), or number of hospitalizations ($p=0.92$) from those who had never discussed AD's with their HCP. Only one (6.3%) respondent reported that the discussion made him/her feel at all uncomfortable. The respondent was most frequently the initiator of the discussion (11 [61.1%]). The HCP initiated the discussion in only 3 of the 18 cases (16.7%).

IV. Respondents Who Had Not Previously Discussed AD's With HCP

VA

Although most respondents had never discussed AD's with their HCP (263 [86.2%]), almost half were interested in such a discussion (119 [47.2%]). Those who would welcome discussion had been hospitalized more frequently (mean of 3.714 vs. 3.030, $p=0.014$). Neither age ($p=0.16$) nor self-reported health status ($p=0.87$) were correlated with interest in AD discussion.

Respondents were given a list of reasons for not discussing AD's with their HCP and were asked to select all those that applied to them. The results are listed in Table Four in Appendix A. There were 263 total responses. One hundred forty-nine (56.7%) chose "Did Not Occur To Me To Bring It Up," 58 (22%) chose "Doctor or NP Did Not Bring It Up," thirty (11.4%) chose "Do Not Like Discussing the Issue," 29 (11%) chose "Not Important," 8 (3%) chose "Too Nervous To Bring It Up," 6 (2.3%) chose "Never Enough Time, and 38 (14.4%) chose to write in a response. The most frequent write-in responses were that the patient had already discussed the matter with his/her attorney (7 [2.7%]) or family (8 [3%]).

HMO

Although most respondents had never discussed AD's with their HCP (136 [88.3%]), almost two-thirds were interested in such a discussion (84 [65.6%]). Neither age ($p=0.59$), self-reported health status ($p=0.23$), nor number of hospitalizations ($p=0.92$) were correlated with interest in discussion.

Respondents were given a list of reasons for not discussing AD's with their HCP and were asked to select all those that applied to them. The results are listed in Table Four in Appendix A. There were 160 total responses. Ninety-seven (60.6%) chose "Did Not Occur To Me To Bring It Up," 33 (20.6%) chose "Doctor or NP Did Not Bring It Up," 4 (2.5%) chose "Do Not Like Discussing the Issue," 4 (2.5%) chose "Not Important," 2 (1.3%) chose "Too Nervous To Bring It Up," 10 (16%) chose "Never Enough Time, and 12 (7.5%) chose to write in a response. The most frequent write-in responses were "too young" (2 [1.3%]), and "discussed with family" (2 [1.3%]).

V. Discussions With Others Regarding AD's

VA

Approximately half of the 299 respondents had discussed their wishes regarding AD's with at least one other person (145 [48.5%]). The most frequent confidants were a

spouse (90 [30.1%]), another family member (80 [26.8%]), a friend (23 [7.7%]), attorney (15 [5%]), or a significant other (11 [3.7%]).

HMO

Almost two-thirds of the 147 respondents had discussed their wishes regarding AD's with at least one other person (93 [63.3%]). The most frequent confidants were a spouse (59 [40.1%]), another family member (68 [46.3%]), a friend (28 [19.0%]), and an attorney (3 [2.0%]).

VI. Preferences Regarding Future Discussion of AD's

VA

When asked whether they or the HCP should initiate the discussion of AD's, most respondents felt that they should bring it up themselves (153 [52.8%]). Only 64 respondents (22.1%) felt the HCP should initiate the discussion. Fifty respondents (17.2%) selected both the "HCP" and "myself" choices. Twenty-three respondents (7.9%) felt that no discussion was necessary at all. Please refer to Figure One in Appendix A for a pie chart of this information.

Most respondents thought that an office visit was an appropriate setting for discussion of AD's (166 [55.9%]). Ninety-one (30.6%) felt that the most appropriate time to discuss AD's was during a hospital admission or after becoming very ill. Eighteen (6.1%) thought it was never appropriate to discuss AD's with their HCP. Please refer to Figure Three in Appendix A for a bar graph of this information.

Most wanted to learn more about AD's, indicating interest in sample documents (125 [40.9%]), brochures (126 [40.9%]), or video tapes (9 [17.5%]). Only 91 respondents (29.5%) replied that they needed no additional information about AD's.

Respondents were asked who else should be involved in the discussion of AD's with their HCP. Please refer to Table Five in Appendix A. A strong majority of respondents thought that their spouse or other family member should be included in this

discussion (228 [74.0%]). Other responses included a friend (17 [5.8%]), a clergy member (14 [4.5%]), and an attorney (11 [3.6%]).

HMO

When asked whether they or the HCP should initiate the discussion of AD's, the most popular response was that they should bring it up themselves (72 [47.4%]). Only 40 respondents (26.3%) felt the HCP should initiate the discussion. Twenty-nine respondents (19.1%) selected both the "HCP" and "myself" choices. Ten respondents (6.6%) felt that no discussion was necessary at all. Please refer to Figure Two in Appendix A for a pie chart of this information.

Most respondents thought that an office visit was an appropriate setting for discussion of AD's (100 [68.0%]). Thirty-three (22.4%) felt that the most appropriate time to discuss AD's was during a hospital admission or after becoming very ill. Only two respondents (1.4%) thought it was never appropriate to discuss AD's with their HCP. Please refer to Figure Three in Appendix A for a bar graph of this information.

Most wanted to learn more about AD's, indicating interest in sample documents (76 [47.5%]), brochures (90 [56.3%]), or video tapes (36 [22.5%]). Only 24 respondents (15%) replied that they needed no additional information about AD's.

Respondents were asked who else should be involved in the discussion of AD's with their HCP. Please refer to Table Five in Appendix A. A strong majority of respondents thought that their spouse or other family member should be included in this discussion. Other responses included a friend (18 [11.3%]), a clergy member (11 [6.9%]), and an attorney (4 [2.5%]).

DISCUSSION

I. Patient Interest in AD's and Preferences for Discussing Them

As discussed in the introduction, several investigations have shown that patients do not understand CPR very well, a central procedure for advance directives⁶⁻¹¹. To further investigate patients' understanding of end-of-life decisions, this study examined the patient's level of understanding of AD's. Most indicated that they had thought previously about what sort of treatment they would want near the end of life (67% at VA, 71.3% at HMO). Although few had even heard of the term "advance directive (41.2% at VA, 27.9% at HMO)," respondents more frequently recognized the terms "living will (88.2% at VA, 88.1% at HMO)" and "power of attorney (73.7% at VA, 70.3% at HMO)." Bearing this in mind, HCP's may discuss AD's more effectively by using the terms "living will" and "power of attorney." Most people are not as informed as they would like to be about AD's and are eager to learn more about them. At least 70% of the respondents felt that they wanted more information about AD's. However, it is difficult to determine how to educate patients adequately about as complex a decision process as end-of-life care. As Figure Three in Appendix A shows, there is much more to promoting AD's than educating people about terminology. While most have heard of living wills, few have them.

While the completion of an AD was not associated with age, number of hospitalizations, or self-reported health status at the VA, the completion of AD was associated with increased age at the HMO (mean age 65.7 vs. 50.5 $p < 0.05$). This may be due to the fact that the HMO's population was over ten years younger than the VA's (54.3 vs. 64.8). Perhaps the typical age for completing AD's is closer to 64 than 54, so that a younger population would be more likely to display an association than an older population would. For instance, if everyone who completed an AD was around 64 years old and the study population was also around 64 years old, there would not be as strong of a distinction in age between those who had completed an AD and the rest of the

population, than if the study population happened to be younger.

One way to help patients better understand issues regarding AD's would be to discuss them with their doctor. This rarely happened in the outpatient setting (13.8% at the VA and 11.7% at the HMO). However, the discussion went well from the patient's perspective when it did happen. Of the patients who had had this discussion, only 14.6% at the VA and 6.2% at the HMO found their discussion to be at all uncomfortable. This finding concurs with previous research²⁵⁻²⁷. Anderson et al. reported that “..patients who sign the AD are not those with lower psychological well-being, and signers do not experience a decline in well-being as a result of their decision (Anderson 1994, p.771).” There was no demographic association for those few patients who felt uncomfortable, concurring with other previous studies of patient preferences regarding AD's. This lack of association is not surprising, however, given the small sample size of those felt uncomfortable.

This makes it difficult to determine in advance who would feel uncomfortable with such a discussion, but several studies have discussed particular cultures for whom such a discussion would be an especially sensitive subject²⁸⁻³⁰. Blackhall et al.²⁹ found that Korean-Americans and Mexican-Americans were less likely than African-Americans or European-Americans (28% and 41% vs. 60% and 65%) to believe that patients should make decisions about the use of life support. Carrese³⁰ et al. describe that 86% of Navajos in a focused ethnography considered advance care planning to be a dangerous violation of traditional Navajo values.

As noted previously, most patients in this study had not discussed advance directives with their doctor. Of those, almost half at the VA and almost two-thirds at the HMO were interested in such a discussion. There are several possibilities for the difference in interest at the VA and at the HMO. One such explanation is interviewer bias, as previously discussed. Another possibility is that gender, the main demographic difference between the two sites, played a role. Perhaps women are more interested in

such a discussion than men. The older mean age for the VA may also have contributed, but this seems unlikely, considering that age at the VA was not associated with interest in discussing AD's. Regardless of the difference in interest between the VA and HMO, a large portion of patients who had not discussed AD's with their doctor were interested in doing so.

Although only 6-15% of those who had actually discussed AD's found the discussion uncomfortable, it would still be useful to predict who would not like to discuss advance planning in order to avoid an unwanted discussion. Unfortunately, interest in discussion was not associated with age, gender, race, self-reported health status, or hospitalization frequency. This lack of demographic association concurs with the findings of Lo²⁶ and Emanuel³¹.

Patients preferred to initiate discussion of AD's with their doctors (153 [52.8%] at the VA, (72 [47.4%] at the HMO). See Figure 2 in the appendix. Indeed, when patients did discuss AD's with their HCP, the respondent most frequently initiated the discussion (20 [47.8%] at the VA and 11 [61.1%] at the HMO). However, several other results from this study suggest how difficult it is for a patient to initiate a discussion about AD's with their HCP. Most had been seeing their HCP for more than a year (63.1% at the VA and 75.9% at the HMO), and many of those who had not already discussed AD's wanted to discuss them with their HCP (119 [47.2%] at the VA and 84 [65.6%]) at the HMO). If patients prefer to initiate the discussion, patients have an ongoing relationship with their HCP's, and patients say they want to discuss them, then why have so few discussions taken place? Indeed, one study analyzing all the questions that 62 patients asked of their HCP's during office visits failed to record a single question about AD's³².

There are several possible explanations for this paradox of patients' apparent interest in initiating the discussion while rarely actually doing so. Perhaps the results of previous studies are closer to the truth; they reported that most patients preferred that the HCP initiate the discussion³³⁻³⁶. Furthermore, it is possible that patients were only

voicing interest in such discussions but in actual practice were not interested enough to bring them up. However, only 11% at the VA and 2.5% at the HMO agreed that the issue was not important to bring up. Possibly, people did not have AD's on their mind at the time of previous visits, but upon reflection considered it a good idea to initiate a discussion. Indeed, the most popular explanation for why a discussion had not taken place was that it did not occur to them to bring it up (56.7% at the VA and 60.6% at the HMO). In any event, while most patients indicated that they would prefer to initiate the discussion, the dearth of previous discussions with MD's suggests that patients have not been able to do so.

Since many patients expressed interest in learning more about advance directives and in discussing them with their HCP, we also wanted to know in what clinical setting they would like the discussion to take place. Fifty-five point nine percent of the VA population and 68% of the HMO population preferred to have the discussion take place as an outpatient. Thirty point six percent at the VA and 22.4% at the HMO preferred the discussion to take place after becoming very ill or as an inpatient. This preference for discussing AD's as an outpatient is not as strong as has been reported in previous studies about patients' preferences. For example, Johnston et al.³⁶ reported that 84% of a general medicine clinic population believed the discussion should occur when the patient is healthy. Shmerling⁶, Kohn³³, Stolman³⁴, and Gamble³⁵ also reported that about 80% preferred to discuss AD's when healthy. In any event, most patients in this study and previous studies think that the best time to discuss end-of-life decisions is not at the very end of life but rather while one is reasonably healthy and away from the stresses of the hospital. However, these discussions have not been taking place. Considering the generally positive response to previous discussions and the number of people who are interested in the discussion, most patients would likely welcome the HCP's initiation of a discussion of AD's.

To further elucidate patients' preferences for discussing AD's with their HCP, we

asked if they would like anyone else to be involved in such a discussion. Not surprisingly, most preferred to include a spouse or other immediate family member in the discussion (VA 74%) This underscores the need for HCP's in the outpatient setting to plan ahead for such a discussion and invite such a family member to participate.

In summary of patients' preferences, most would like more information, those who had discussed them did not find the talk uncomfortable, and about half to two-thirds of those who had not discussed them would like to do so. The patients preferred to initiate the discussion themselves, and most would like to discuss them in an outpatient setting with a family member present.

II. Differences Between the VA and HMO

There are several potentially important demographic differences in the populations at the VA and HMO. First, the VA population is older. There were also many more males at the VA. Those at the VA had been with their current HCP for a shorter period of time than for those at the HMO.

Aside from these demographic differences, there were also differences in the way the data was obtained at each setting. For example, one investigator administered all the questionnaires at the VA, while another interviewer administered all the questionnaires at the HMO. This opens any comparisons between the two populations to interviewer bias. It is also important to recall that no data was obtained on those who refused to participate at the HMO, including how many refused. Also, not all persons attending the clinic were approached. It is possible that the HMO captured a different portion its study population than at the VA, confounding any comparisons between the two study populations. Therefore, we have kept all data separate.

III. Barriers to Communication

There is a central paradox to patients' interest and preferences regarding the discussion of AD's: if so many are interested in the discussion, why has so little discussion taken place? We asked the patients why they thought such a discussion had not taken place. One potentially concerning barrier to discussion was whether the participant had previous contact with their HCP. Fortunately, there were few "first visits" to the HCP at either the VA (12.7%) or the HMO (5.1%). Indeed, most had known their HCP for at least a year (63.1% at the VA, 71% at the HMO), enough time for a discussion to have taken place.

Through these results and through review of the literature, several other barriers to discussion are apparent.

A. It Did Not Occur To Them

The first barrier is simple; patients usually do not think about discussing end-of-life treatment preferences with their HCP. As table 3 shows, the most popular explanation for not discussing these issues with their HCP was that it did not occur to them to bring it up. Perhaps patients think that discussing AD's with their HCP is a good idea, but not foremost of their concerns, much like cleaning the attic seems to be a good idea but never seems to actually get done. After all, 67% at the VA and 71.3% at the HMO had thought about their own preferences for treatment near the end of life, and many are interested in the discussion when asked.

Possibilities for future research include assessing explanations for why it did not occur to patients to discuss AD's. Perhaps it has not occurred to people to discuss this issue with their doctor because they feel they are too young or healthy for such a discussion. Another factor may be that it is so unusual in the normal discourse between HCP and patient to discuss dying that the setting does not invoke thoughts leading to a discussion.

Conversely, perhaps there is a pervasive, underlying fear of dying undergirding discussions with one's HCP, so that such any thoughts of such a discussion are repressed from one's conscious thoughts. This explanation seems less likely when one considers how unusual it was for the discussions that have actually happened to be discomforting to the patient. If people did not think about discussing AD's because of a fear of death, one might anticipate that those who had actually discussed AD's with their HCP would have found the discussion to be uncomfortable. Furthermore, roughly half to two-thirds of those who had not previously discussed AD's with their HCP expressed interest in doing so when asked. One might expect that people who avoided initiating a discussion of AD's due to a fear of death would not express interest in such a discussion when asked.

B. The HCP Did Not Bring It Up

The second-most popular response explaining why a discussion did not take place was that their doctors had not brought it up. These two most frequently mentioned explanations for not discussing AD's, not thinking of it and the doctor not bringing it up, could be overcome if the HCP initiated the discussion. These two barriers account for 65% of the explanations at the VA and 81% of the explanations at the HMO.

C. The Patient Does Not Value the Discussion

Some patients explained that the discussion had not taken place because they did not want it to take place. There were a couple of response categories that involved negative feelings towards advance directive discussion: the discussion was not important and they do not like discussing the issue. These responses accounted for 19% of the responses at the VA and 5% at the HMO. A small but significant group does not want to discuss AD's.

D. The HCP's Perceived Barriers

These barriers are somewhat different from those mentioned by physicians in a study set in a resident clinic²⁰. In this study the most frequent explanations were "too little time," "not enough continuity," and "patients not sick enough." These residents'

explanations do not attribute ignorance (it not occurring to them to bring it up) or deference to the patient's initiation of the discussion (the patient did not bring it up), as the patients did. Rather, the residents' explanations implied that the discussion was not as important as other issues to discuss (not enough time) or was not appropriate to discuss (not enough continuity or patient not sick enough). The difference in explanations between the physicians and patients can certainly be ascribed to the fact that the two studies studied different populations.

It may also reflect, however, a difference in priorities between the physician and the patient regarding discussing advance directives. The patients have not thought to mention it to the physician or are leaving it up to the physician to bring it up. This suggests a lack of awareness of the issues and a deference to those considered to be the "experts" for such issues, the physicians. The physicians, meanwhile, do not seem to value the discussion enough to initiate one. It seems possible that this may have lead to a negative feedback loop for discussing AD's. Patients do not understand AD's and defer to the physicians; physicians do not value the discussion and do not help the patient to understand them.

IV. Conclusion

Although it is not easy to predict who wants to discuss AD's and who does not, HCP's should offer to discuss them routinely with their patients. The vast majority of patients react favorably to the discussion, many are interested in discussing them, and the main barriers to discussing them from a patients' perspective could be overcome by HCP initiation. HCP's could also try to empower patients to initiate the discussion of AD's with their HCP. Examples of such empowerment include providing educational materials or making preliminary discussions with a nurse or social worker available to the patient. Considering that most patients preferred to include a relative or friend in such a

discussion, HCP's should encourage the patient to bring a significant other to the discussion.

The SUPPORT study demonstrated that the presence of an AD as well as an involved intervention to facilitate discussion did not improve adherence to the patients' wishes during actual end-of-life decisions. Equally as important, however, these interventions did not seem to improve communication between the patient and the HCP. For patients to be able to participate in their own end-of-life decisions, HCP's must make it a priority to offer to establish an ongoing dialog with their patients about these issues. While AD's may not lead to an improved outcome by themselves, better communication between the HCP and the patient may increase the likelihood that the patients' preference will actually be followed.

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Table One: Summary of Various Interventions Upon AD's

Authors	n	Design	Setting	Intervention	Outcome
Siebert 1996	36	Randomized Cohort Trial	Extended Care Center	AD video	No significant change in CPR preferences or comprehension of AD's
Meier 1996	190	RCT	Elderly Inpatients	Counseling re:AD's upon admission	Increased reporting of previous AD's and completion of new AD's (6% vs. 48%)
Reilly 1995	1780	Time-Series Intervention Trial	Acute-care Inpatients	Reminders, education, feedback to physicians	Increased frequency of AD's in chart (23.5% to 62.5%)
Landry 1997	187	RCT	Uninformed Outpatient Clinic	1-hour seminar, pamphlets, and AD forms	Increased completion (24% vs. 38%) and discussion of AD's (57% vs. 73%)
Rubin 1994	1101	RCT	HMO	Mailed pamphlet and AD forms	Increased completion of AD (0.4% vs. 18.5%)
Sachs 1992	131	RCT	Geriatric Clinic	Mailed educational forms and reminder notes	No significant difference
Dunn 1996	120	Time-Series Intervention Trial	Primary Care Physicians and Nurses	Coversheet For Discussiong AD's	Increased agreement between provider and patient in theoretical health scenarios when using the coversheet
Meier 1996	687	Observational Study of an Intervention in a Convenience Sample	Geriatric Clinic	Physician counselling about AD laws, distribution of educational materials and AD forms	Increased frequency of AD's in the chart (2.3% to 31.5%)
Sulmasy 1996	62*, 187**	Controlled Clinical Trial *residents ** patients	Internal Medicine Resident Clinic	Educational pamphlets for patients and lectures and videos of sample discussions for residents	No significant change in patient-education group, and increased discussion of AD's in resident-education group (3% to 17%)
Markson 1994	10	Observational Study of an Intervention in a Convenience Sample	Primary Care Physicians and Nursing Home Physicians	Sample discussion of AD's	Increased discussion of AD's between physican and patient (0% vs. 21%)
SUPPORT 1995	9105	Prospective Observational Study, then a Controlled Clinical Trial	Five Teaching Hospitals	R.N. discussions of AD's with patients, updated 6-month survival estimates to physicians, and CPR outcome estimates to physicians	No significant change in five different outcome measures looking at actual end-of-life decision making

Table Two: Effect of the SUPPORT Phase II Intervention on Five Outcomes: Intervention Group vs. Control Group, 1992-1994

	Adjusted Ratio (95% CI)
Median time until DNR order was written	1.02 (0.90-1.15)
DNR agreement, %	1.22 (0.99-1.49)
Undesirable states, median	0.97 (0.87-1.07)
Pain, %	1.15 (1.00-1.33)
Resource use, median 1993 dollars	1.05 (0.99-1.12)

Table Three: Demographics

	VA-Refused	VA-Participators	HMO
Age	67.61	64.75 (sd 11.38)	54.31 (sd 17.6)
Gender			
Male	100%	97%	34%
Female		3%	66%
Race	N/A		
African-American		10.2%	19%
Caucasian		86.6%	70%
Hispanic/Latino		1.6%	4.5%
Religion			
Catholic	67%	58.7%	49.9%
Jewish	4%	3.3%	13.4%
Not Affiliated	17%	10.2%	6.2%
Protestant	12%	24.8%	22.4%
Marital Status			
Never Married	15%	13.1%	11.9%
Married	60%	60.1%	60.4%
Divorced	16%	17.6%	17.0%
Widowed	7%	9.2%	10.7%
Unknown	2%	0%	0%
Education Level	N/A		
Grade School		15.7%	6.3%
High School		49.7%	43.8%
College		34.6%	50.0%
Length of Time With Present HCP	N/A		
First Visit		12.7%	5.1%
< 1 Year		24.2%	19.0%
> 1 year		63.1%	75.9%
Hospitalizations	N/A	3.45 (sd 2.25)	3.01 (sd 2.29)
Self-reported Health	N/A	5.69	7.16

N/A = Not Available

Table Four: Reasons For Not Discussing AD's

	VA (n=263)	HMO (n=160)
Did Not Occur To Me To Bring It Up	149 (56.7%)	97 (60.6%)
Doctor or NP Did Not Bring It Up	58 (22%)	33 (20.6%)
Do Not Like Discussing the Issue	30 (11.4%)	4 (2.5%)
Not Important	29 (11%)	4 (2.5%)
Too Nervous To Bring It Up	8 (3%)	2 (1.3%)
Never Enough Time	6 (2.3%)	10 (16%)
Other (write-in)	*38 (14.4%)	**12 (7.5%)
Total Responses	318	161

*The most frequent write-in responses were that the patient had already discussed the matter with his/her attorney (7 [2.7%]) or family (8 [3%]).

**The most frequent write-in responses were "too young" (2 [1.3%]), and "discussed with family" (2 [1.3%]).

Table Five: Who Else Should Be Included
When Discussing AD's With Your HCP?

	VA	HMO
Spouse	54.2% (167)	57.5% (92)
Other Family	39.6% (122)	65.0% (104)
No Discussion Necessary	11.4% (35)	3.8% (6)
Just Me	9.7% (30)	13.1% (21)
Friend	5.8% (18)	11.3% (18)
Clergy	4.5% (14)	6.9% (11)
Attorney	3.6% (11)	2.5% (4)

Figure One: Who Should Initiate The Discussion at the VA?

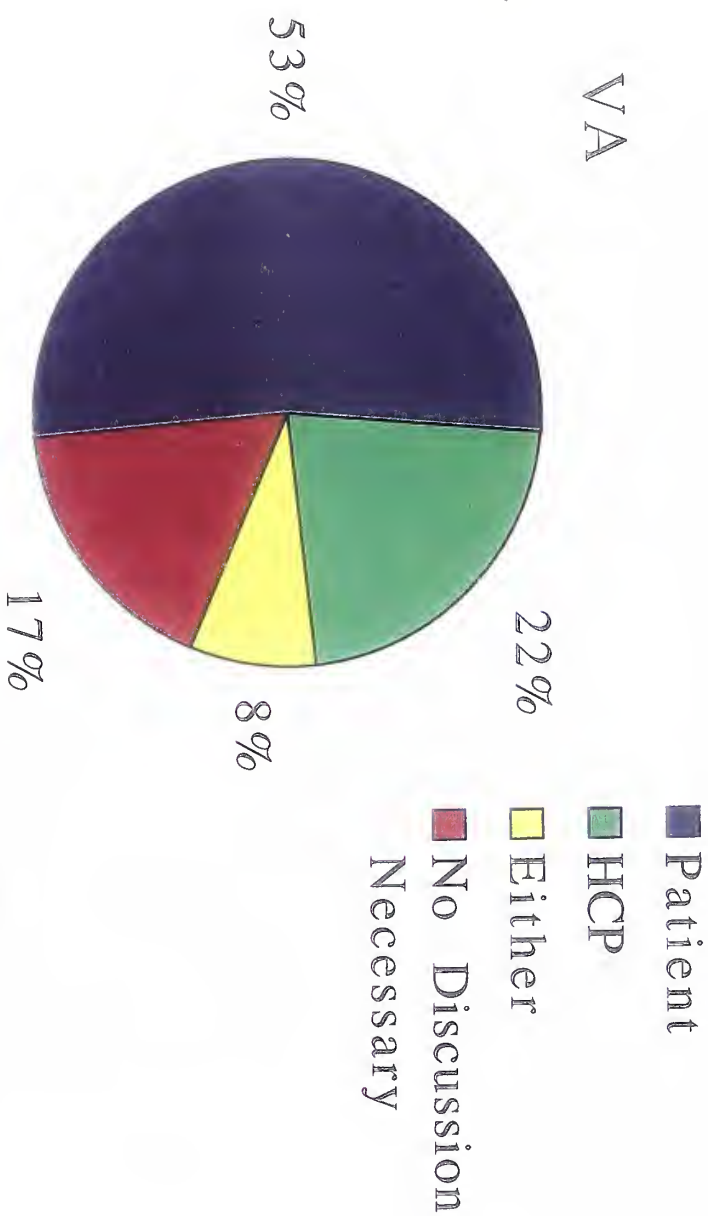


Figure Two: Who Should Initiate The Discussion at the HMO?

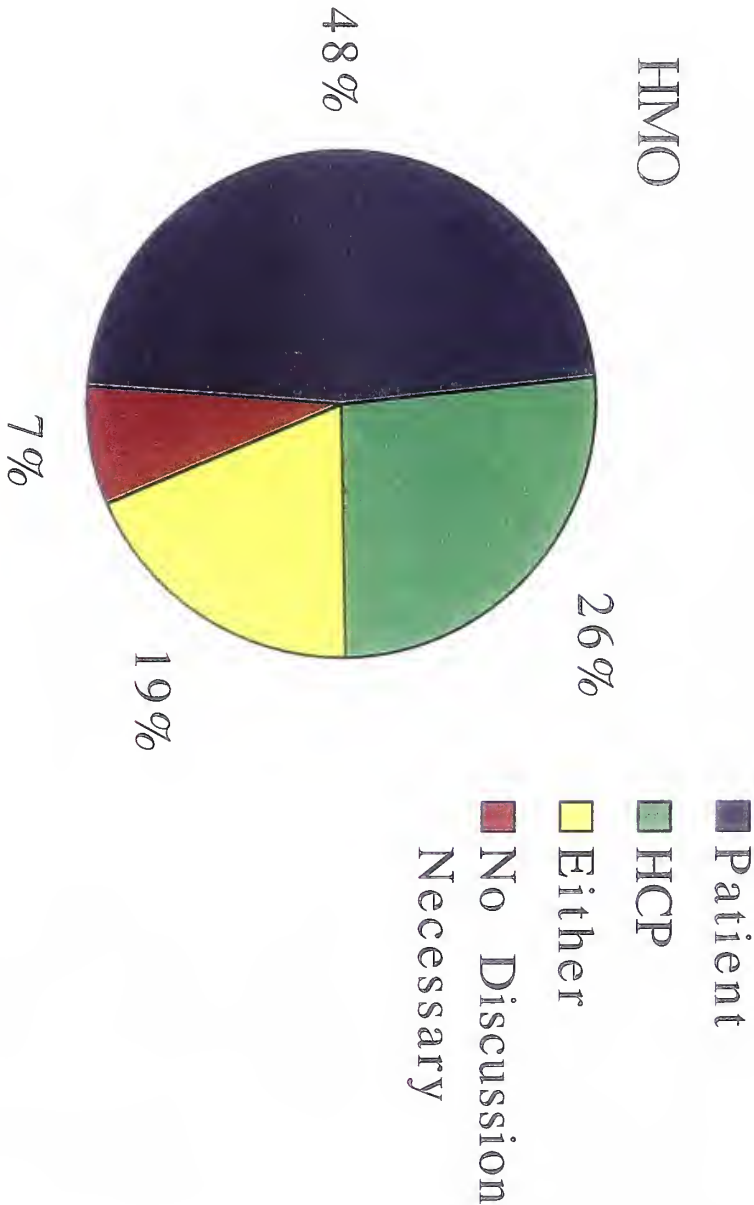


Figure Three: Where Should The Discussion of AD's Take Place?

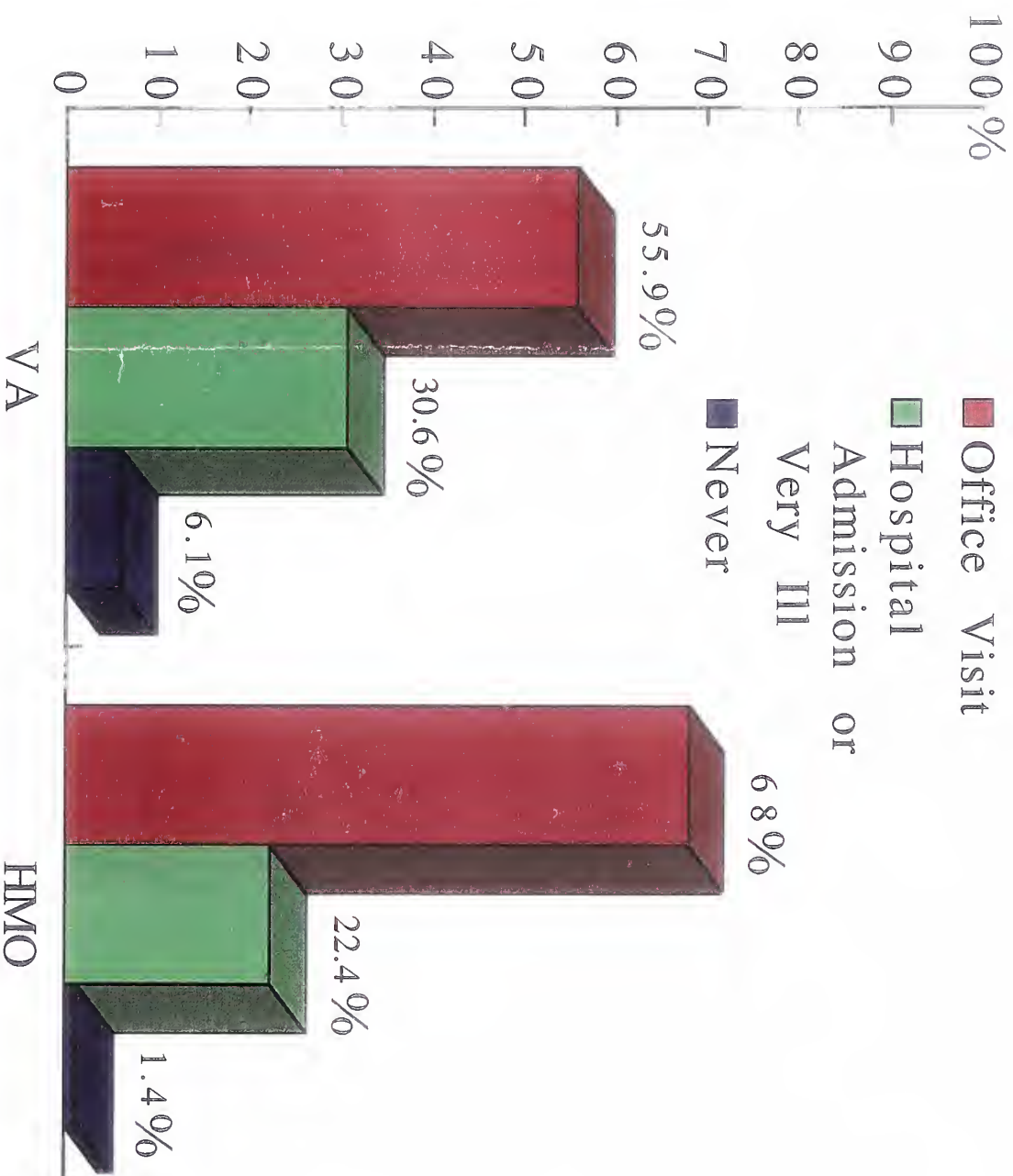
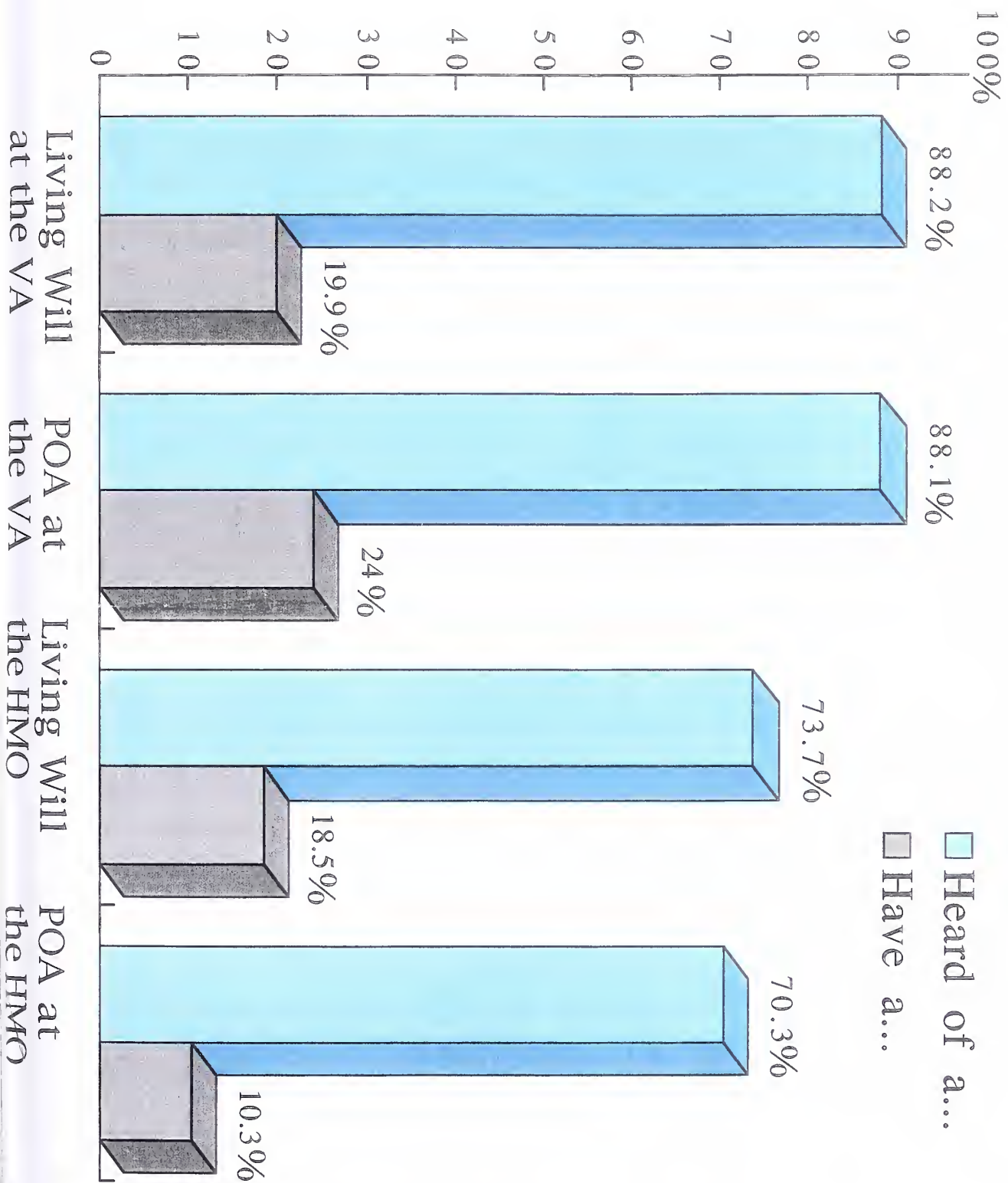


Figure Three: Awareness and Prevalence of AD's



SURVEY:
Outpatient's Preferences Regarding Advance Directive Discussions

What is an advance directive?

An advance directive is a legal document through which you may provide directions or wishes as to your medical care. It is used when you are unable to make or communicate your decisions about your medical treatment due to a medical crisis.

An advance directive does not necessarily mean that you *refuse* medical treatment in the case of a serious illness, but rather *makes your wishes about treatment known* if you are unable to communicate them yourself (because of memory loss, serious illness, or other condition).

There are two main types of advance directives:

(1) The Living Will:

The living will is a statement describing your treatment preferences if you are unable to communicate them yourself. Living wills often include preferences regarding the use of life support such as respirators and feeding tubes in a medical crisis. It may also include preferences regarding resuscitation.

(2) The Durable-Power-Of-Attorney-For-Health-Care:

The-durable-power-of-attorney-for-health-care is a statement naming a certain person to make decisions for you should you be unable to do so yourself. Unlike the living will, it does not describe your actual preferences, but rather designates someone to communicate those preferences on your behalf.

Directions: Please complete the following questions as honestly as possible. If you do not understand a question, please do not hesitate to ask for assistance.

1. Have you ever, before today, heard of advance directives?	YES	NO
2. Have you ever, before today, heard of living wills?	YES	NO
3. Have you ever, before today, heard of powers-of-attorney-for-health-care?	YES	NO
4. Have you ever thought about what sort of treatment you would want if you developed a life-threatening illness?	YES	NO
5. Do you have a living will?	YES	NO
6. Do you have a power-of-attorney-for-health-care?	YES	NO
7. Have you ever discussed your wishes regarding living wills or powers-of-attorney-for-health-care with your doctor or nurse practioner?	YES	NO

If YES then please answer questions A and B below.

- A. Who initiated the discussion?
- ☐ me
 - ☐ my doctor or nurse practioner
 - ☐ other_____
- B. How did the discussion make you feel?
- ☐ comfortable
 - ☐ slightly uncomfortable
 - ☐ very uncomfortable
 - ☐ neutral

If NO then please answer questions C and D below.

- C. Why have you not discussed living wills or powers-of-attorney-for-health-care?
- ☐ not important
 - ☐ never enough time
 - ☐ my doctor or nurse practioner did not bring it up
 - ☐ I was too nervous to bring it up
 - ☐ I do not like discussing the issue
 - ☐ It did not occur to me to bring it up
 - ☐ other_____
- D. Would you like to discuss living wills or powers-of-attorney-for-health-care with your doctor or nurse practitioner?
- YES NO

<p>8. Have you ever discussed your wishes regarding living wills or powers-of-attorney-for-health-care with any other person?</p>	<p>YES NO</p>
<p>If YES then please complete Question A</p>	<p>If NO then please continue to Question 9.</p>
<p>A. Please check off all other people with whom you discussed living wills or powers-of-attorney-for-health-care.</p> <ul style="list-style-type: none"> <input type="checkbox"/> spouse <input type="checkbox"/> other family member <input type="checkbox"/> friend/friends <input type="checkbox"/> significant other <input type="checkbox"/> clergyperson <input type="checkbox"/> social worker <input type="checkbox"/> nurse <input type="checkbox"/> other _____ 	
<p>9. Who do you think should initiate discussion about living wills or powers-of-attorney-for-health-care?</p> <ul style="list-style-type: none"> <input type="checkbox"/> myself <input type="checkbox"/> my doctor or nurse practioner <input type="checkbox"/> no discussion is necessary 	
<p>10. When do you think discussions between you and your doctor or nurse practioner about living wills or powers-of-attorney-for-health-care should take place?</p> <ul style="list-style-type: none"> <input type="checkbox"/> first office visit <input type="checkbox"/> yearly check-up <input type="checkbox"/> any office visit <input type="checkbox"/> special visit for this purpose <input type="checkbox"/> on admission to the hospital <input type="checkbox"/> only if I become very ill <input type="checkbox"/> never <input type="checkbox"/> other (write in) _____ 	

11. Whom else should be involved in discussions regarding living wills or powers-of-attorney-for-health-care? (Check all that apply)

- ☐ no discussions are necessary with anyone
- ☐ no one else; just myself and my doctor or nurse practioner
- ☐ spouse
- ☐ other family
- ☐ friends
- ☐ clergypeople
- ☐ social workers
- ☐ nurses
- ☐ other _____

12. What would you find helpful to learn more about living wills or powers-of-attorney-for-health-care? (Check all that apply)

- ☐ nothing additional
- ☐ sample documents
- ☐ brochures
- ☐ video tapes
- ☐ other (write in) _____

13. Compared to all the topics you have to discuss with your doctor or nurse practioner, how important is discussing living wills or powers-of-attorney-for-health-care? (Place a mark on the line)

Not at all _____ The most
important important

Thank you very much for your time and answers.

End of survey.

Please help us complete the following information about yourself:

¹⁴ Age ---

¹⁵ Sex ☐ male ☐ female

¹⁶ Marital status

- ☐ never married
- ☐ married
- ☐ divorced or separated
- ☐ widowed

¹⁷ How long have you been seeing your present doctor or nurse practitioner?

- ☐ this is my first visit
- ☐ less than one year
- ☐ between one and five years
- ☐ more than five years

¹⁸ Religion

- ☐ Catholic
- ☐ Jewish
- ☐ Not Affiliated
- ☐ Protestant
- ☐ Other (write in) _____

¹⁹ Race

- ☐ African-American
- ☐ Caucasian
- ☐ Hispanic/Latino
- ☐ Other _____

²⁰ Check highest education completed:

- ☐ grade school
- ☐ high school
- ☐ college/specialized training

²¹ How many times have you been hospitalized as an adult?

- | | |
|--------------------------------------|--|
| <input type="checkbox"/> never | <input type="checkbox"/> four times |
| <input type="checkbox"/> one time | <input type="checkbox"/> five times |
| <input type="checkbox"/> two times | <input type="checkbox"/> six times |
| <input type="checkbox"/> three times | <input type="checkbox"/> more than six times |

²² Please rate your health at this time (Place a mark on the line)

I have a life-threatening illness _____ I am completely healthy

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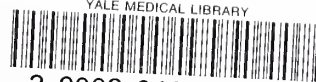
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